



# Emma Martin

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# My Physical Invisible Disability

When I was in 5th grade, my mom took me to a doctor because I had been complaining of foot pain after dance class. We were told that I had extremely flat feet and short Achilles tendons, which was causing my feet to invert inward, creating the pain. The doctor recommended low impact sports, such as swimming, as well as physical therapy, but assured my mother that my diagnosis probably wouldn't have a great effect on me until late in my life, most likely when I was to reach old age.

He couldn't have been more wrong.

Flash-forward ten years, and I am now a sophomore in college. I followed the doctor's orders, was a competitive swimmer throughout high school, and also had intermittent physical therapy. I had pretty much forgotten about having flat feet because it had no effect in my life. But this all changed when I turned twenty. I started to have severe pain in my feet, to the point where I couldn't walk to classes and had trouble putting weight on my feet for the first hour or so that I was awake.

I went to see an orthopedic doctor with my mom, where I had many X-rays. This first appointment revealed that I had numerous tiny stress fractures running throughout both of my feet, presumably causing a lot of the pain I was in. But the doctor suspected that it was more than just the fractures causing the pain, so we set up an appointment with a different doctor who specialized in podiatry, and I was sent on my way with a boot to be worn on each foot for two months.

At the time, my knowledge of disability was quite basic. I had taken high incidence and low incidence disability courses, and I interacted with disabled people regularly by spending time with my aunt, who has cerebral palsy, and by working with clients as a music therapy student. I readily categorized disability as autism, Down's syndrome, and cerebral palsy, to name a few, but I had never dived into the realm of what makes someone disabled, and I had certainly never thought of myself as having a disability. At this point in my life, I did not "feel" disabled, similar to how people in the Deaf culture, who identify as members of a distinct community not because they 'hate' disability, or view disabled people as 'less worthy', but because they do not 'feel' disabled" (Deal).

When I visited the podiatrist, he was quick to diagnose me with tendonitis. He wanted to bypass orthotics altogether and go straight into leg braces. The braces were made of plaster, colored tan to blend in with my skin tone, and laced up the front. I could only wear them with three pairs of shoes, all of which had to be bought a size and half larger than my foot size.

I despised these braces. I had never felt more exposed, more vulnerable, more in pain, than when I was wearing them. I covered them up at all costs and rarely showed my legs in public anymore. But the worst part was that they didn't help anything. The braces pressed in on my swollen tendons and made my skin itchy from where I would sweat and the plaster would stick to my skin. I constantly needed to take sitting breaks during classes and was consistently ten minutes late to classes, even though I was practically jogging to get to them.

But if it hadn't have been for these braces, I wouldn't have discovered something about myself: I am disabled. The devices that were supposed to help me disabled me. The classes where I was supposed to learn about disability disabled me. My professors who told me I wasn't allowed to sit during class disabled me. I finally allowed myself to become disabled, and in that, found ways to help myself. This is where my experience differs from people of the Deaf community- I do feel disabled by the world around me.

I registered with the office for students with disabilities, which gave me the following accommodations: the ability to sit during class, the ability to leave class for short periods of time, the ability to stand during class, the ability to miss class for doctor appointments, and the ability to make up any assignments I might miss due to a medical appointment. I ditched the braces, and the doctor, for a new podiatrist who actually listened to me and found options that worked for me. Additionally, I also acquired a new disability: arthritis, found by an MRI my new doctor had prescribed.

I cried when I got the phone call from the nurse telling me I had arthritis. I cried because old people had arthritis, not twenty-year-olds. I cried because I knew it would only get worse from here. And I cried because finally, finally, I had a definitive answer.

I have flat feet, short Achilles tendons, tendonitis, and arthritis. I am disabled. According to an article by Verbrugge and Juarez, "arthritis-disabled people are older and more likely female than other-disabled people, they have substantially more health and disability problems, their work participation is lower, and they are more likely to self-identify as disabled", making me a paradox for being diagnosed with arthritis at a young age. According to the same study, the mean age for a person with arthritis is 66.7 years old, and the prevalence of adults 18-24 being diagnosed with arthritis is only 0.1% (Verbrugge and Juarez). This data may be discouraging for a twenty-year-old diagnosed with arthritis; however, the article also states that 72.7% of people with arthritis are female, and that "arthritis-disabled people have more chronic conditions than other-disabled people," possibly explaining why I have the co-morbid condition of tendonitis. Something else I find interesting is that only 43.1% of people with arthritis identify as having a disability, perhaps because arthritis is usually thought of in relation with old age (Verbrugge and Juarez). I feel that my youth may contribute to the impact of my disability because it is another anomaly added to my experience.

As noted, the stereotypical image of someone with disabling arthritis an old person, maybe in a wheelchair, possibly in a nursing home, and the data largely supports this alignment of age and arthritis. Almost no one envisions a blonde, blue-eyed twenty-year-old college student. Possibly because of this, arthritis is not thought of as a disability; it's thought of as a side effect of aging and possibly another reason why a little less than half of the people with arthritis identify as being disabled. This thought process makes my disability even harder to grasp or understand. In an article by Bruni, he writes about an older woman, who has lost much of her mobility due to old age, "maybe they see in her their worst fears about their own futures" (2). The combination of my youth and arthritis may exacerbate people's fears, further causing them to shy away from me and build defenses in response to my arthritis-disability.

I was just beginning my junior year when I first heard of invisible disability.

The Psychology club was holding a weeklong event to bring awareness to invisible disability, or depression and anxiety, as was depicted by the posters. It was also around this time that I enrolled in an Intro to Gender Studies course. In this class, we briefly discussed the difference in society's reactions to visible versus invisible disability, something which I had started to see in the mental health awareness rise but hadn't fully explored yet.

It's worth mentioning that up to this point I hadn't had the best reactions from people when I told them I had a disability. My parents thought I was being dramatic, most of my professors thought I was lying, and my friends brushed it off or, in one case, laughed and said, "You shouldn't say that when there are people out there with actual disabilities." Having these reactions to my "coming out" as disabled made me feel as if I had made the wrong choice; my experience of identifying as disabled was diminished by other people's opinions. These reactions also lowered my self-esteem, as a newly disabled woman. According to Nosek et. al., "On average [women with disabilities] reported lower self-esteem than women without disabilities" (Nosek et. al.). The reactions I was experiencing are not uncommon for disabled people, and clearly our society is perpetuating a hierarchy by imposing low self-esteem onto disabled people while reinforcing a visible/invisible binary that makes invisible or less visible disabilities the subordinate term.

In an article by Grue et. al., they discuss the hierarchy of disability from an able-bodied perspective: "We find that there is prestige hierarchy of chronic diseases and disabilities in the disability field. In this hierarchy, somatic conditions that are strongly associated with medical treatment were placed higher than either conditions that are characterized by permanence, or conditions are associated [that] with psychosomatic etiologies" (Grue et. al.). What this article is telling us is that people prefer disabilities that they can readily understand; they can point to an answer or cause, and that makes them feel better about the disability. And if I'm being honest, my disability is one that, according to the research, is slightly "preferred." According to the same article, arthritis was ranked 16 out of 38 in "prestige" (Grue et. al.).

Furthermore, in an article by Deal, in examining research conducted by Tringo (1970), he concurred that "ulcer, arthritis, and asthma ranked as most accepted" (898), and that conclusion still stands 30 years later (Thomas).

I find these research conclusions both comforting and concerning at the same time. On one hand, it is nice to know that my disability is "preferred." I find comfort in knowing that future employers and friends/family will most likely not view my disability in a negative sense. This opens up many doors for me and fortifies a positive future. On the other hand, however, is my disability "preferred" because you can't see it? Or is it because it has a definitive medical definition, or cause? People want to feel secure in their thinking, and "our prejudices often exist to make us feel better" (Snyder-Grant).

I have learned that people with mental disabilities are stigmatized because people can't see their disability. I have also learned that mental disabilities are invisible disabilities. It wasn't until Intro to Gender Studies, when we briefly discussed different reactions to disability, that I had this realization: "This is it. This is why people are so confused when I tell them I have a disability."

I am an anomaly. I don't fit the mold.  
I have an invisible physical disability.

This realization is something that I have really struggled with. With which group do I identify? Do I identify with people who have mental disabilities, usually classified as "invisible" that I can relate to on a stigmatized basis, or people with physical disabilities, usually classified as "visible", that I relate to on a diagnostic/prognostic basis? And what if I choose a group to identify with based on a hierarchy I have unconsciously created in my mind? Snyder-Grant discusses her own prejudice by saying "even those of us with disability compare ourselves to one another. 'At least I'm able to walk' can give me a false sense of superiority" (Snyder-Grant). I feared I would choose the wrong side of the dichotomy and be rejected by fellow disabled people. But should I even have to choose a group to identify with at all -- can I not just identify as disabled?

My experiences with disability contradict what society expects. Society loves a clean, black and white answer. It rejects grey areas. It creates dichotomies as if they can really impose order on a chaotic world. Annie Delainey, a Youtuber, has many similar experiences to myself. She also feels unsure of whether her disability is visible or invisible, or both, stating, "I am this weird in-between point of visible and invisible disability" (theannieelainey). I frequently fall victim to this dichotomy. I wonder where I belong in the dichotomy of disability, instead of looking at disability as a spectrum. "People don't know the amount of diversity that is within the disabled community" (theannieelainey), and I think that "forgetting" that diversity helps to create two dichotomies – ablebodied/nondisabled and visible/invisible – that are thrust upon people with disabilities.

I think it is possible to experience your disability as both visible and invisible. Hilde Zitzelsberger interviewed fourteen women about their experiences of embodiment with physical disabilities. A common theme arose out of the interviews, which "indicated that lived dimensions of in/visibility were not separate or sequential but occurred simultaneously throughout their lives" (Zitzelsberger). This is something I can personally relate to. Depending on the day, the severity of my pain, the latest diagnosis, my disability can be either "visible" or "invisible". My disability is "invisible," but there have been times when I have worn boots, or braces, which have then made by disability visible. The separation seems superficial; if I'm experiencing both, why not just refer to it as my disability?

The problem with a dichotomy of disability, physical or mental, visible or invisible, is that it leaves out many people. It rejects people who don't fit the mold, who experience both invisible and visible disability. Why are we not talking about this more? Why in a class I recently took focused on Disability Studies am I not reading more about people to whom I can relate? There have only been a few articles I have related to, having been about Black and disabled women, who feel that feminism rejects them both because of their race and their disability. I relate to these women because I feel rejected too, but not by feminism. I feel rejected by Disability Studies. I feel that, on some level, and maybe unconsciously, the field rejects people who don't fit the visible/invisible, physical/mental dichotomy. "We, as disabled people, may need to acknowledge our own prejudices before we can truly demand a wholly inclusive society" (Deal).

This dichotomy, or segregation of disability, forced upon us in an ableist culture creates unwelcomed tension between people with disabilities, a community that should ideally be unified in a common desire to break down stereotypes and prejudices. Snyder-Grant writes about being scared of people thinking she may have muscular dystrophy instead of multiple sclerosis, stating that "MS is more romantic than muscular dystrophy" (Snyder-Grant). But, as Deal states, "if we accept there is nothing inherently 'wrong' in being a disabled person, then being viewed as one subgroup or another, based on impairment, should not, in theory, cause anxiety or insult" (Deal). Maybe looking at disability more as a spectrum can assist with decreasing the tension between people with diverse kinds of disabilities.

In order to truly understand people with disabilities, to truly dive into cultural perceptions of disability, we need to do away with this dichotomy of disability that has been thrust upon us. We cannot accommodate, nor fully include, until we first reject these dichotomies. As Deal states, "such action is likely to further isolate those perceived as less accepted by society, creating a further level of social oppression, but this time from within one's own community" (Deal). We need to study, simply, people with disabilities, and not then separate them into limited taxonomic rubrics which serve to contain them. Only when we break down the visible/invisible, physical/mental categories can we truly begin to study disability, and how it affects people. Disabled people may be wary of this idea of viewing disability as a spectrum;

they may worry that this will diminish their personal experience of disability. But I believe that looking at disability as a spectrum does not ignore the sub-groups of disability or the people who relate because of their similar disability experiences. Deal voices a couple of other important questions that relate to my topic and should be given more consideration: "do disabled people regard themselves as part of an in-group of disabled people, an in-group of those with the same impairment, or as part of an out-group (i.e. not associated with disability)?" (Deal). Or, could it even be a combination of all three? The fundamental purpose of Disability Studies is to learn about disability as a social construct, to examine how society makes someone disabled, how it produces disability.

If Disability Studies scholars integrate societal construct of disability in their examinations -- visible/invisible, physical/mental -- then they fail to reach their purpose from the outset. For example, if a Disability Studies scholar decides to write a piece about "invisible disability" and how it is viewed by the majority of society, but the piece only focuses on mental disabilities, such as depression, anxiety, and bipolar disorder, then the scholar has used the societal construct of "invisible/mental disability" in order to attempt to break down another societal construct. This piece would, therefore, become less valid because it fails to address all invisible disabilities and reinforces an unnecessary and damaging binary in doing so, using one absolutist societal construct in an attempt to break down another.

Everyone's experience of disability is different, but I reject the idea that these experiences categorize us. Disability Studies has done a good job of analyzing the hierarchies of disability that society creates. But in continuing to use a disability dichotomy, Disability Studies as a field too often reinforces a hierarchy- that of easily classified disability versus people who don't fit the ready-made mold. All data points to a hierarchy of disability within the disabled community, of people with physical disabilities, or easily explained disabilities, being preferred over people with mental disabilities, or disabilities that cannot be easily explained. I am not saying that the project of breaking down the hierarchy of mental versus physical disability is not a valid one, especially in the disabled community. But I am saying that in challenging that hierarchy, we are forgetting about a whole group of people who are then no longer a part of the conversation.

In regard to whether there should be sub-groups in the disability community, I believe further research is required as to whether or not society creates these sub-groups in order to more easily understand and manage disability. I am just one person, and I do not pretend to be an expert in Disability Studies, nor do I claim that my experience speaks for anyone other than me. However, these strike me as pressing and important issues. Deal states that we should "[expand] our knowledge with respect to the degree to which we, disabled people, see ourselves as homogenous in-group, as a set of separate impairment group or, possibly, as not holding a disabled identity at all" (Deal). I agree.

We must begin to consider how our current ways of conceiving of disability does not account for all who are disabled., I cannot be molded into a category of disability. And because of this, my experience of disability is too often forgotten about, discarded, treated as if it is neither real nor valid. Until Disability Studies rejects a disability dichotomy, it will continue to follow a social construct that categorizes people in unnecessarily limited, which goes against the fundamental purpose of the field and undermines our efforts to dismantle ableism generally.

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